

Committee on Children Public Hearing

March 6, 2014

Testimony in SUPPORT of SB 285

Submitted by: Alicia Martinez, BSW Student at Southern Connecticut State University

Good day members of the Committee on Children. Thank you for granting me this opportunity to speak. My name is Alicia Martinez and I am an undergraduate student at Southern Connecticut State University, majoring in Social Work. I am testifying in support of SB 285.

According to data from Hunter's Hope Foundation, approximately one in 100,000 live births in the United States are afflicted with Krabbe Disease (also known as globoid cell leukodystrophy), and close to one out of 125 in the U.S. carry the genetic deficiency that causes the disease. The National Center for Advancing Transitional Sciences reports that many infants affected by Krabbe Disease experience muscle weakening, difficulty moving, chewing, swallowing and breathing, as well as vision loss and intellectual disability, which can often lead to death before the age of 2. Therefore, in effort to detect this disease earlier on, it is vital that globoid cell leukodystrophy screening tests are administered soon after birth.

The opposition may counter this proposition and possibly voice concerns regarding the fiscal effect of expanding the statewide screening of newborns to include Krabbe Disease. However, by doing so there could potentially be significant improvements in medical outcomes and future costs. If screening tests could help in the early detection of this disease, affected individuals may have the opportunity to receive treatment and therapy, which can in turn improve the quality of life. In addition, implementation of screening tests for Krabbe Disease may also reduce future treatment costs for families and public health care programs.

By expanding newborn screening programs to include screening for Krabbe Disease, the state can anticipate a significant decrease in health care costs for children affected with the disease, and an increase in the quality of life many, with the appropriate care, treatment, and therapy. Therefore, I support SB 285 to include Krabbe Disease (globoid cell leukodystrophy) in newborn screening tests, statewide, and I encourage this committee to vote this bill favorably out of committee.

Thank you for your time,

Alicia Martinez